

AMENDED IN SENATE APRIL 22, 2013

AMENDED IN SENATE APRIL 1, 2013

SENATE BILL

No. 222

Introduced by Senator Padilla

February 11, 2013

An act to add ~~Section 56.19 to~~ *Chapter 2.6 (commencing with Section 56.18) to Part 2.6 of Division 1 of the Civil Code*, relating to genetic information.

LEGISLATIVE COUNSEL'S DIGEST

SB 222, as amended, Padilla. Genetic information: privacy.

Existing law prohibits discrimination on the basis of an individual's genetic information. Existing law protects the genetic test result contained in the medical records of an applicant to, or enrollee of, a health care service plan. Existing law establishes civil and criminal penalties for the negligent or willful disclosure of a persons genetic test results, as specified.

This bill would *enact the Genetic Information Privacy Act, which would declare that an individual's genetic information is protected by the right of privacy. The bill would prohibit any person from collecting, storing, analyzing, or disclosing genetic information without the written authorization of the individual to whom the information pertains, and would include related findings and declarations. It also would prescribe specific circumstances under which genetic information may be collected, stored, analyzed, or disclosed without the authorization.* The bill would establish civil and criminal penalties for a violation of ~~this prohibition~~ *its provisions*. By creating new crimes, this bill would impose a state-mandated local program.

The California Constitution requires the state to reimburse local agencies and school districts for certain costs mandated by the state. Statutory provisions establish procedures for making that reimbursement.

This bill would provide that no reimbursement is required by this act for a specified reason.

Vote: majority. Appropriation: no. Fiscal committee: yes.
State-mandated local program: yes.

The people of the State of California do enact as follows:

1 SECTION 1. The Legislature finds and declares all of the
2 following:

3 (a) On October 11, 2012, the Presidential Commission for the
4 Study of Bioethical Issues (commission) released a report titled
5 “Privacy and Progress in Whole Genome Sequencing,”
6 recommending the adoptions of policies to help ensure privacy
7 and security, as the field of genomics advances.

8 (b) Various national and state policies are in place to protect
9 personally identifiable health information and records.

10 (c) The commission urges federal and state governments to
11 ensure a consistent floor of privacy protections covering whole
12 genome sequencing data regardless of how they were obtained.

13 (d) Policies should protect individual genetic information by
14 prohibiting the unauthorized use of surreptitious collection.

15 (e) It is the intent of the Legislature to enact legislation that
16 would protect individuals from the unauthorized collection, storage,
17 and disclosure of their genetic information.

18 (f) It is the intent of the Legislature to enact legislation that
19 would ensure that genetic information is personal information that
20 is not collected, stored, or disclosed without the individual’s
21 authorization.

22 (g) It is the intent of the Legislature to enact legislation that
23 would provide protections for the collection, storage, and
24 authorized use of genetic information.

25 (h) It is the intent of the Legislature to enact legislation that
26 would promote the use of genetic information for legitimate
27 reasons, including, but not limited to, health care, research,
28 advancement of medicine, and educational purposes, as the field
29 of genomics advances.

30 ~~SEC. 2. Section 56.19 is added to the Civil Code, to read:~~

1 ~~56.19.— (a) Genetic information is protected by the right of~~
2 ~~privacy pursuant to Section 1 of Article I of the California~~
3 ~~Constitution and, notwithstanding subdivision (c) of Section 56.10,~~
4 ~~or any other law, shall not be collected, stored, analyzed, or~~
5 ~~disclosed without the written authorization of the individual to~~
6 ~~whom the information pertains.~~

7 ~~(b) Any person who negligently violates subdivision (a) shall~~
8 ~~be assessed a civil penalty in an amount not to exceed one thousand~~
9 ~~dollars (\$1,000) plus court costs, as determined by the court, which~~
10 ~~penalty and costs shall be paid to the individual to whom the~~
11 ~~genetic information pertains.~~

12 ~~(c) Any person who willfully violates subdivision (a) shall be~~
13 ~~assessed a civil penalty in an amount not less than one thousand~~
14 ~~dollars (\$1,000) and not more than five thousand dollars (\$5,000)~~
15 ~~plus court costs, as determined by the court, which penalty and~~
16 ~~costs shall be paid to the individual to whom the genetic~~
17 ~~information pertains.~~

18 ~~(d) Any person who willfully or negligently violates subdivision~~
19 ~~(a), where the violation results in economic, bodily, or emotional~~
20 ~~harm to the individual to whom the genetic information pertains,~~
21 ~~is guilty of a misdemeanor punishable by a fine not to exceed ten~~
22 ~~thousand dollars (\$10,000).~~

23 ~~(e) In addition to the penalties listed in subdivisions (b) and (c),~~
24 ~~a person who commits an act described in subdivision (b) or (c)~~
25 ~~shall be liable to the person to whom the genetic information~~
26 ~~pertains for all actual damages, including damages for economic,~~
27 ~~bodily, and emotional harm that is proximately caused by that act.~~

28 ~~(f) Each violation of this section is a separate and actionable~~
29 ~~offense.~~

30 ~~(g) (1) No person or entity who sends or discloses genetic~~
31 ~~information in a good faith attempt to comply with this section~~
32 ~~shall be liable under this section for the conduct of the recipient.~~

33 ~~(2) No person or entity that receives genetic information in a~~
34 ~~good faith attempt to comply with this section shall be liable under~~
35 ~~this section for the conduct of the sender or discloser.~~

36 *SEC. 2. Chapter 2.6 (commencing with Section 56.18) is added*
37 *to Part 2.6 of Division 1 of the Civil Code, to read:*

CHAPTER 2.6. GENETIC PRIVACY

- 1
2
3 56.18. (a) *This chapter shall be known, and may be cited, as*
4 *the Genetic Information Privacy Act.*
- 5 (b) *For purposes of this chapter, the following definitions apply:*
- 6 (1) *“Deidentified data” is health information that does not*
7 *identify an individual, with respect to which there is no reasonable*
8 *basis to believe that the information can be used to identify an*
9 *individual.*
- 10 (2) *“DNA sample” means a tissue, fluid, or other bodily sample*
11 *of an individual on which a DNA analysis can be carried out.*
- 12 (3) *“Genetic characteristic” means any scientifically or*
13 *medically identifiable gene or chromosome, or alteration thereof,*
14 *that is known to be a cause of a disease or disorder, or that is*
15 *determined to be associated with a statistically increased risk of*
16 *development of a disease or disorder, and that is presently not*
17 *associated with any symptoms of any disease or disorder.*
- 18 (4) (A) *“Genetic information” means information about any*
19 *of the following:*
- 20 (i) *An individual’s genetic tests.*
- 21 (ii) *The genetic tests of that individual’s family members.*
- 22 (iii) *The manifestation of disease or disorder in family members*
23 *of the individual, generally referred to as family medical history.*
- 24 (iv) *An individual’s request for, or receipt of, genetic services,*
25 *or the participation in clinical research that includes genetic*
26 *services by the individual or a family member of the individual.*
- 27 (v) *The genetic information of a fetus carried by an individual*
28 *or by a pregnant woman who is a family member of the individual*
29 *and the genetic information of any embryo legally held by the*
30 *individual or family member using an assisted reproductive*
31 *technology.*
- 32 (B) *Genetic information does not include information about the*
33 *sex or age of the individual, the sex or age of family members, or*
34 *information about the race or ethnicity of the individual or family*
35 *members that is not derived from a genetic test.*
- 36 (5) *“Genetic service” means a genetic test, genetic education,*
37 *or genetic counseling, including obtaining, interpreting, or*
38 *assessing genetic information.*

1 (6) “Genetic test” means a genetic test; genetic counseling,
2 including obtaining, interpreting, or assessing genetic information;
3 or genetic education.

4 (7) “Person” means a natural person, trust or estate,
5 partnership, corporation, professional association or corporation,
6 or other entity, public or private.

7 56.18.1. (a) Genetic information is protected by the right of
8 privacy pursuant to Section 1 of Article I of the California
9 Constitution and, notwithstanding subdivision (c) of Section 56.10,
10 or any other law, shall not be collected, stored, analyzed, or
11 disclosed without the written authorization of the individual to
12 whom the information pertains.

13 (b) Any person who negligently violates subdivision (a) shall
14 be assessed a civil penalty in an amount not to exceed one thousand
15 dollars (\$1,000) plus court costs, as determined by the court, which
16 penalty and costs shall be paid to the individual to whom the
17 genetic information pertains.

18 (c) Any person who willfully violates subdivision (a) shall be
19 assessed a civil penalty in an amount not less than one thousand
20 dollars (\$1,000) and not more than five thousand dollars (\$5,000)
21 plus court costs, as determined by the court, which penalty and
22 costs shall be paid to the individual to whom the genetic
23 information pertains.

24 (d) Any person who willfully or negligently violates subdivision
25 (a), where the violation results in economic, bodily, or emotional
26 harm to the individual to whom the genetic information pertains,
27 is guilty of a misdemeanor punishable by a fine not to exceed ten
28 thousand dollars (\$10,000).

29 (e) In addition to the penalties listed in subdivisions (b) and (c),
30 a person who commits an act described in subdivision (b) or (c)
31 shall be liable to the person to whom the genetic information
32 pertains for all actual damages, including damages for economic,
33 bodily, and emotional harm that is proximately caused by that act.

34 (f) Each violation of this section is a separate and actionable
35 offense.

36 (g) Any person or entity that wishes to obtain genetic
37 information, other than a person or entity authorized to receive
38 genetic information pursuant to subdivision (h), shall obtain a
39 valid authorization for the release of that information. The written

1 authorization required by this subdivision shall do all of the
2 following:

3 (1) Be written in plain language and in a typeface no smaller
4 than 14-point type.

5 (2) Be dated and signed by the individual or a person authorized
6 to act on behalf of the individual.

7 (3) Specify the types of persons authorized to disclose
8 information about the individual.

9 (4) Specify the nature of the information authorized to be
10 disclosed.

11 (5) State the name or functions of the persons or entities
12 authorized to receive the information.

13 (6) Specify the purposes for which the information is being
14 collected.

15 (7) Specify the length of time the authorization shall remain
16 valid.

17 (8) Advise the person signing the authorization of the right to
18 receive a copy of the authorization.

19 (h) (1) Genetic information may be collected, stored, analyzed,
20 or disclosed without the authorization required by subdivision (g),
21 in accordance with paragraph (2), provided that the entity may
22 collect, store, analyze, or disclose the information only for the
23 purposes specified. Use for any other purpose is subject to the
24 authorization required by subdivision (a).

25 (2) Genetic information may be collected, stored, analyzed, or
26 disclosed under this subdivision, as follows:

27 (A) By a law enforcement official or correctional officer in the
28 execution of his or her official duties consistent with existing law.

29 (B) By a hospital, laboratory, or physician carrying out
30 court-ordered tests for genetic information.

31 (C) By a licensed health care professional, as defined in Section
32 56.05, in a medical emergency.

33 (D) By a coroner or medical examiner, in the execution of his
34 or her official duties consistent with existing law.

35 (E) For purposes of any screening of a newborn infant required
36 by state or federal law.

37 (F) If the information is in the form of deidentified data.

38 (G) By any person or entity covered by and required to comply
39 with any of the following:

1 (i) *The Health Insurance Portability and Accountability Act of*
2 *1996 (Public Law 104-191).*

3 (ii) *Section 56.11 of the Confidentiality of Medical Information*
4 *Act (Part 2.6 (commencing with Section 56)).*

5 (iii) *Section 791.13, 10123.35 or Article 2.6 (commencing with*
6 *Section 10146) of Chapter 1 or Part 2 of Division 2 of the*
7 *Insurance Code.*

8 (iv) *Section 50.25 of Title 21 of the Code of Federal Regulations.*

9 (v) *Section 46.116 of Title 28 of the Code of Federal*
10 *Regulations.*

11 SEC. 3. No reimbursement is required by this act pursuant to
12 Section 6 of Article XIII B of the California Constitution because
13 the only costs that may be incurred by a local agency or school
14 district will be incurred because this act creates a new crime or
15 infraction, eliminates a crime or infraction, or changes the penalty
16 for a crime or infraction, within the meaning of Section 17556 of
17 the Government Code, or changes the definition of a crime within
18 the meaning of Section 6 of Article XIII B of the California
19 Constitution.